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## ***Kidney Patients Expand Impact on R & D***

***Largest Patient Meeting Showcases Role September 21-23, 2022***

***Patient Insight Data Shapes New Generation of Drugs, Devices, and Diagnostics***

**Washington, D.C.** - One of the most medically vulnerable populations in America, people living with kidney diseases, is rewriting the book on scientific research and medical innovation by aggressively expanding their impact on basic research, applied research, and the key regulatory and payment deliberations that determine when safe, new products reach the market. Kidney patients have support from a growing national and global alliance of research professionals, kidney medicine experts, elected and career government officials, and private industry executives and investors who respect patients and view their insights and advocacy as the catalysts driving long-overdue cures for kidney diseases and transformations in kidney health.

The American Association of Kidney Patients (AAKP), the oldest and largest independent kidney patient organization in the U.S., has expanded patient impact on kidney research and development by organizing and training patients to engage effectively with leaders in science and innovation. AAKP is a staunch advocate for patient care choice, independence, and new treatments that allow patients to fully pursue their aspirations, including part-time or full-time work. AAKP will highlight some of the key research and development activities kidney patients are involved in at its Annual National Patient Meeting, being held virtually September 21-23, free of charge to all registrants (<https://bit.ly/AAKPNPM>). Speakers at the meeting include some of the top kidney research and innovation experts, federal officials, and national patient experts.

AAKP founded its Center for Patient Education and Research in 2016 to serve as a rapid fulfillment hub for government, academic, medical device manufacturers, and pharmaceutical industry requests to engage kidney patient experts. The Center also supports AAKP's efforts to speed the utilization of unique patient insight data across both the product development lifecycle and within regulatory and payment decisions, including those made by commercial insurers ([read now](#)). Since its launch, AAKP has dramatically expanded its membership databases, social media recruitment, and analytics tools. The organization now services dozens of requests every year for clinical trial awareness and recruitment campaigns, patient advisory boards, technical evaluation panels, focus groups, patient surveys, clinical research, and public policy research. AAKP leaders and staff provide expert advice to organizations and companies on how to work meaningfully with patients as co-investigators and partners and offer [online training](#) for patients on how to be equally effective collaborators.

"AAKP patient members have near unlimited opportunities to impact science and innovation. We are proud their diverse and unique perspectives are shaping research and development and new products destined for the market. Both patients and their doctors want to cure kidney diseases, and both are impatient for the arrival

of safe, new treatment choices,” stated [Richard Knight](#), President of AAKP and a 16-year kidney transplant recipient. Knight is co-chair of the Patient and Family Affairs Subcommittee for the Scientific Registry of Transplant Recipients (SRTR).

At the federal level, AAKP patients are impacting research and development initiatives across the Departments of Health and Human Services (HHS), the Department of Veterans Affairs (VA), and the Department of Defense (DOD) via the Congressionally Directed Medical Research Program (CDMRP) and other DOD activities. Further, AAKP has been actively involved in patient engagement initiatives and the development of patient insight data alongside the U.S. Food and Drug Administration (FDA), the Centers for Medicare and Medicaid Services (CMS), the Centers for Disease Control and Prevention (CDC), the Health Resources and Services Administration (HRSA), and multiple other federal agencies. To facilitate greater veteran involvement in kidney research and innovation and to support the VA kidney medicine program in the U.S. Congress, AAKP launched its [Veterans Health Initiative](#) in 2017.

AAKP leaders and AAKP Ambassadors are also closely involved in leading national kidney innovation partnerships and consortiums, including the Kidney Health Initiative (KHI), a partnership of the FDA and the American Society of Nephrology (ASN); the KidneyX Innovation Accelerator, a partnership of the ASN and HHS; and the Kidney Precision Medicine Project (KPMP), a scientific consortium funded by the National Institutes of Health (NIH)/National Institute of Diabetes and Digestive and Kidney Disease (NIDDK). The KPMP is America’s largest taxpayer-supported kidney science initiative. Together, these efforts are resulting in significant advancements in kidney care through science, new precision medicine, artificial organs, and human-centered product design ([read now](#)).

AAKP has forged strong partnerships with numerous universities and academic centers involved in kidney-related studies. AAKP patients are presently involved in research at the George Washington University School of Medicine and Health Sciences, University of Washington, Emory University, University of Pennsylvania, University of Pittsburgh, University of Michigan, Duke University, Wake Forest University, University of Michigan, Northwestern University, University of California San Francisco, Vanderbilt University, University of California Los Angeles, University of Minnesota, Virginia Tech, and various other institutions. Through the Patient-Centered Outcomes Research Institute (PCORI), AAKP patient advocates have been involved in every PCORI-funded kidney research effort since PCORI authorization in 2010 and reauthorization in 2019 ([read now](#)). AAKP forecasts its involvement in university research efforts will more than double by 2024.

Globally, since 2019, AAKP has organized patient consumers and advocacy organizations to support research and clinical trials through its *Annual Global Summit on Kidney Disease Innovations*, a partnership event with the George Washington University School of Medicine and Health Sciences. The *Global Summit* has evolved into the largest patient-led kidney disease conference in the world and has a reach of over 90 countries. In 2022, the *Global Summit* gained new participants from Nepal, Bosnia and Herzegovina, Iraq, and Kazakhstan ([read now](#)). Since 2021, AAKP has also provided expertise to the World Health Organization (WHO) on the development a new engagement framework designed to elevate the lived experiences and insights of people living with non-communicable disease, including kidney patients, within WHO deliberations and agenda setting ([watch OnDemand](#)). In June of 2022, the European Kidney Health Alliance (EKHA) broadened its involvement in AAKP’s [Decade of the Kidney™](#) initiative by including it in the theme of their annual European Kidney Forum before the European Parliament in Brussels. At the Forum, AAKP leaders joined patients and EU-elected leaders to express support for new treatment innovations, including artificial organs and xenotransplants ([watch OnDemand](#)).

[Edward V. Hickey, III](#), USMC, Vice President of AAKP and Chair of the Veterans Health Initiative, stated, “The COVID-19 pandemic and the associated high fatality rates among kidney patients are a critical reminder of how vulnerable kidney patients are, especially as their disease progresses. AAKP patients are fully committed to investing their time and expertise to help advance science and new treatments. As a national advocacy organization, we are equally committed to making certain safe solutions pass regulatory and payment processes without unnecessary delays and have built the requisite capacities to achieve the mission.” Hickey is a former senior Congressional aide and has served in multiple presidential administrations.

[Paul T. Conway](#), AAKP Chair of Policy and Global Affairs, stated, “Kidney patients know cures and treatment choices will expand only when science and ingenuity flourish and innovation is rewarded. Dialysis, and its accompanying high mortality, has changed little since America put a man on the moon, won the Cold War, and transformed the global economy and communications with modern technology. Kidney patients know this nation can do better—and we also know that if kidney medicine fails to evolve, society will continue to pay a prohibitive cost for inaction, and patients will pay with their lives.” Conway is a 25-year transplant patient, serves on the Kidney Health Initiative (KHI) board, and is a former Chief of Staff for the U.S. Department of Labor.

In the United States alone, an estimated 37 million people have chronic kidney disease, including 800,000 with kidney failure, and whose kidney care costs the American taxpayer over \$100 billion a year. Those costs do not include the additional expense to the nation and patients stemming from workforce dropout, disability, and dependency caused by this chronic illness and the burdens associated with obsolete, status quo technologies found in dialysis care. Immunocompromised kidney patients and immunosuppressed kidney transplant recipients were among the hardest hit by COVID-19, and despite advances in related therapeutics, they remain at high risk of infection.

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**About the American Association of Kidney Patients (AAKP):** Since 1969, AAKP has been the premier patient-led organization driving policy discussions on kidney patient consumer care choice and treatment innovation. AAKP members represent all disease states, ethnicities, and demographic indicators. By 1973, AAKP patients had collaborated with the U.S. Congress and White House to secure dialysis coverage for any person suffering kidney failure, a taxpayer-funded effort that has saved over one million lives. In 2018, AAKP established the largest U.S. kidney voter registration program, KidneyVoters™. Over the past decade, AAKP patients have helped gain lifetime transplant drug coverage for kidney transplant recipients (2020); new patient-centered policies via the White House *Executive Order on Advancing American Kidney Health* (2019); new job protections for living organ donors from the U.S. Department of Labor (2018); and Congressional legislation allowing HIV-positive organ transplants for HIV-positive patients (2013). Follow AAKP on social media at [@kidneypatient](#) on Facebook, [@kidneypatients](#) on Twitter, and [@kidneypatients](#) on Instagram, and visit [www.aakp.org](http://www.aakp.org) for more information.